Title: Sexuality in the Lives of People with Intellectual disabilities: A Meta-Ethnographic Synthesis of Qualitative Studies

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Highlights

- People with intellectual disabilities (PWID) hold traditional views about sexuality and relationships.
- PWID feel under the control of paid and unpaid carers in seeking to express their sexuality.
- A model is presented to understand how cultural contexts influence the expression of sexuality.
- A rights-based context is rarely used in practice or research to positively support PWID's sexuality.

Abstract

Background. The normalisation movement calls for more recognition of the sexual rights of people with intellectual disabilities to challenge classically paradoxical cultural beliefs: 'hypersexual' versus 'asexual'.

Aims. This meta-ethnographic qualitative synthesis aimed to explore the voices of people with intellectual disabilities in regards to their experiences and perceptions of sexuality using a Coordinated Management of Meaning framework to derive new conceptual understandings of how their sexuality exists within multiple contexts.

Methods and Procedures. A systematic literature search and quality assessment yielded 16 studies that met the inclusion criteria and were synthesised following the method of meta-ethnography.

Outcomes and Results. Four core themes were identified; 'Sociocultural Norms'; 'Under Others Power'; 'Sexual Identity' and 'Sexual Experience'.

Conclusions and Implications. Application of the hierarchical Coordinated Management of Meaning model suggested caregivers contextual beliefs about people with intellectual disabilities' sexuality inhibited or facilitated positive expressions of sexuality over and above individual needs and desires. Rights-based cultural messages provided the only context that led to positive sexuality outcomes and research that explores sexuality within this context is much needed. The Coordinated Management of Meaning model identified by this research may act as a framework to support the reflective-practice of caregivers.

Introduction

Sexuality is ever-present in our everyday lives and is a fundamental human right for all ages, genders, sexual orientations and levels of cognitive development (Ailey, Marks, Crisp, & Hahn, 2003). It is a complex area of human experience involving emotions, biology, beliefs, morals and social behaviours strongly influenced by culture and context. A person's sexuality can considerably influence the formation of their identity, self-esteem and relationships (Ailey et al., 2003; Sheehy, 2000).

Sexuality is further complicated by the power embedded within socially constructed meanings of phenomena such as gender and intellectual disabilities. This review will examine how those with intellectual disabilities experience their sexuality. The most recent statistics estimate just under 1 million people with an intellectual disability (PWID) live in the UK (Public Health England, 2016). Living with family or friends is now the most common living arrangement for PWID with long-term social care support. However, living in registered care homes and supported accommodation is still also very common for PWID (Public Health England, 2016).

Whether living at home or in supported accommodation, the lived experiences of PWID are shaped by social norms, often reflected in national and local policy. The normalisation movement led to national deinstitutionalisation for PWID in the 1970s. This change implied a shift in philosophy and ideology which emphasised the rights of PWID to live a 'normal' life and make their own choices (Barr, McConkey, & McConaghie, 2003; McCarthy, 1999; Parley, 2001). Before the 1970s, PWID's sexuality was actively repressed and denied by the segregation of sexes, however this movement recognised the right of PWID to determine their own sexuality. As services moved towards a model of normalisation, services stopped explicitly denying the sexuality of PWID, instead managing the sexuality of PWID based on the social-cultural norms of the non-disabled (McCarthy, 1999). Brown (1994) suggested that normalisation is restrictive when applied to sexuality of PWID, as what is considered 'normal' is determined by mainstream socialisation and variations in sexual expression are not freely accepted. Therefore, a number of researchers have commented that a lack of direction, support, consideration and confidence in how the normalisation principle translates into clinical practice may present as a barrier to the development and expression of sexuality for PWID (Johnson, Frawley, Hillier, & Harrison, 2002; Löfgren-Mårtenson, 2004; Pownall, Jahoda, & Hastings, 2012; Taylor-Gomez, 2012).

The paradoxical views of PWID sexuality

A well-documented paradox exists regarding how services and caregivers often view the sexuality of PWID (Dotson, Stinson, & Christian, 2003). On one hand, PWID are viewed as needing protection from sex as they are viewed as 'asexual' (McCarthy, 1999; Yau, Ng, Lau, Chan, & Chan, 2009) without capacity for sexual desire (Bunyan et al., 1986; McCarthy, 1999; Taylor-Gomez, 2012), but on the other hand, PWID are viewed as 'hypersexual', and that society needs protecting against PWID's sexuality (Lesseliers & Van Hove, 2002; Taylor-Gomez, 2012). These stereotypes may act to sabotage development of a realistic representation of the sexuality of PWID. There is now a third view: that PWID are sexual beings and are capable of, and show, a desire to have positive sexual lives (Deeley, 2002). However, as professionals and caregivers can hold one or all of these views, they may experience conflict over how best to support PWID, and commonly resort to strategies of over-protection (Deeley, 2002; Hollomotz, 2011). Cultural values can impact on the development of sexuality, and the more that PWID are 'protected' from sexuality, the more inexperienced, uneducated, vulnerable and dependent they may become. Therefore, overprotection becomes a self-fulfilling prophecy, disabling PWID from becoming socially and sexually competent.

However, there has been an increase in the positive promotion of PWID sexuality (DOH, 2001, 2009; Executive, 2000; McCarthy & Thompson, 1995). A growing number of self-advocacy groups and qualitative research publications are giving PWID a voice to express their views about sexuality and intimate relationships. Their aim is to reconsider the dominant assumptions of the non-disabled and empower PWID to influence practice, policy and ultimately their own relationships. PWID are aware of their rights to have relationships and want choices about the types of relationships they have and what support they need to have them (Kelly, Crowley, & Hamilton, 2009). Understanding how sexuality functions in the lives of PWID is critical to implementing assistive and supportive services.

The Coordinated Management of Meaning

One model that may be helpful in unpacking how sexuality and intellectual disabilities intersect at the level of society and the individual is the Coordinated Management of Meaning (CMM) (Pearce & Cronen, 1980). CMM proposes that communication is performative in such a way that people co-construct their social realities through the process of communication within a multitude of contexts. CMM is interested in the form of the

communication rather than its content and describes communication acts as ‘doing things’. Therefore, CMM describes communication as not just occurring through language, but as ‘acts’, for example someone choosing to express their sexuality and how they do this would be considered a communication. Communication is also reflexive, in that communicative acts and the social worlds that we create also affect and shape us. The hierarchical model of CMM proposes that meaning is dependent on the context in which it occurs, but that communication acts always occur in multiple contexts. No matter what the speaker says, the words of the story will only make sense if they are understood within the multiple contexts of culture, relationships, personal identity and momentary episodes. The layers of context are an essential component of CMM theory as the higher contextual levels have a greater influential force than the lower ones (the contextual force). Therefore, if culture is the highest context, the cultural messages about the sexuality of PWID will have more influence over the relationships, identities and episodes of sexuality. Whilst CMM began as an interpretive communication theory, it has now been established as a practical theory aiming to join people in various systems and situations to articulate the knowledge needed to act constructively.

To illustrate how CMM can be applied to explore how people engage in meaning-making across multiple contexts we can examine research exploring discrimination across cultural groups (Orbe & Camara, 2010). For example, one participant, a white male, became aware that a black colleague was using racial slurs as communicative acts but was initially unsure whether this was due to race or being new to the job. The white male was unable to make sense of the episodes of derogatory racial communication until he was able to reflect on the acts within their wider contexts of identity, relationships and culture. His identity as a white male that differed to the identity of the black colleague, the power imbalance in their relationship and the positive relationships between the black colleague and other black colleagues (even if new employees) and an increasing awareness of the segregated culture of the workplace, all contributed to the white male’s meaning making that he was being discriminated against due to race. Additionally, this process was reflexive, for example the segregated culture shaped the meaning of the racial communicative acts, just as the communicative acts shaped the segregated culture.

Study Purpose

Research concerning sexuality in PWID has often been conducted from the perspective of caregivers. This study deliberately aimed to identify research articles that prioritised the voice of PWID. As this body of research tends to be qualitative and with small

participant numbers the method of meta-ethnography appeared most appropriate to synthesis PWID's voices and experiences of their sexuality. Additionally, by applying the practical theory of CMM as a framework to guide the synthesis, the authors aimed to use a hierarchical model to elaborate multiple meanings and stories of sexuality, evaluate how stories of PWID's sexuality can be interconnected, recognise which context is privileged and why, and make suggestions to intervene and improve practices.

Method

Systematic literature search

In order to identity relevant studies to be included in the review a systematic search of the published literature was conducted in July 2016. A combination of search terms was generated (Table. 1). The initial search yielded a large number of papers that were filtered down (Figure. 1) to a final list of articles to be included in this review (Table. 2).

Table. 1. *Search Terms*

	Search Terms	**Search Criteria**
	Learning Disability* OR LD OR Intellectual Disability*	All dates Article titles
AND	Intimate* OR close* OR sexual* OR Sex OR Love* OR sexuality*	
AND	Experience* OR Qualitative	

Inclusion criteria

Studies that met the following inclusion criteria were included in the review:

- Studies that employed a qualitative methodology (e.g. interviews, focus groups etc) or mixed method (provided the qualitative results were reported separately).
- Published in peer-reviewed journals.
- Written in English.
- Studies which had adults with intellectual disabilities as the primary informant; if articles included participants under the age of 18 and the data had not been separately analysed, articles were excluded.

- Studies that specifically focused on sexuality or intimate, romantic or sexual relationships.
- Studies not primarily focused on instances of sexual abuse or rape.
- Studies focused on a community sample (not including people in secure services).

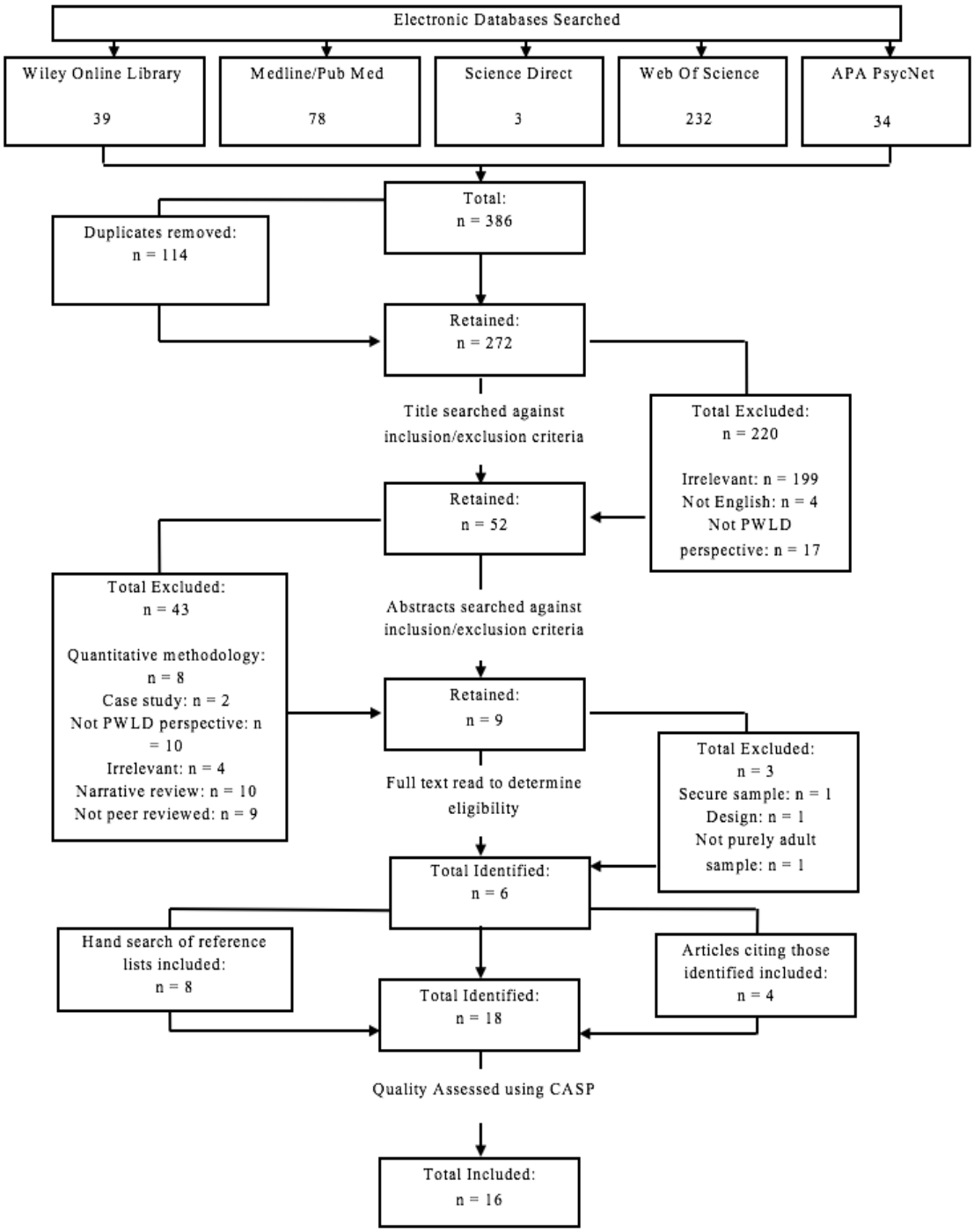

Figure 1. Systematic search

Table. 2. *Summary information of the papers included in the meta-ethnography*

Reference	Title	Country	Sample	Recruitment	Data Collection	Analysis	Aim	CASP Score
Study 1 Bernert (2011)	Sexuality and Disability in the Lives of Women with Intellectual Disabilities	USA	14 women	Referred by rural agencies that provided assistive and supportive services	Ethnographic, in-depth interviews, formal observation and focus groups	Grounded Theory	Explore how intellectual disability influences how women experience their sexuality	12
Study 2 Azzopardi-Lane and Callus (2015)	Constructing sexual identities: people with intellectual disability talking about sexuality	Malta	19 men and women	Self-elected to participate through a self-advocacy group	Inclusive, focus groups	Thematic analysis	To report on the social construction of sexuality of people with learning disabilities	16
Study 3 Healy, McGuire, Evans, and Carley (2009)	Sexuality and personal relationships for people with an intellectual disability. Part 1: Service-user Perspectives	Ireland	32 men and women,	Randomly selected from a service-user database in a community-based service.	Focus group	Not stated	To gather information from people with learning disabilities about their knowledge, experiences and attitudes towards sexuality	15
Study 4 Sullivan, Bowden, McKenzie, and Quayle (2013)	"Touching people in relationships": a qualitative study of close relationships for	Scotland	10 men and women	Self-elected to participate through a self-advocacy group	Semi-structured Interviews	Interpretive phenomenological analysis	To explore the experiences and perceptions of close relationships in people with	20

Reference	Title	Country	Sample	Recruitment	Data Collection	Analysis	Aim	CASP Score
	people with an intellectual disability						learning disabilities	
Study 5 Yau, Ng, Lau, Chan, and Chan (2009)	Exploring sexuality and sexual concerns of adult persons with intellectual disability in a cultural context	Hong Kong	12 men and women	Recruited through opportunity selection from non-government organizations providing specialist services	Semi-structured interviews	Inductive analysis	To examine the issues of sexual activity, marriage and parenthood and how people with learning disabilities learn about their own sexuality.	17
Study 6 Löfgren-Mårtenson (2004)	"May I?" About sexuality and love in the new generation with intellectual disabilities	Sweden	13 young adults	Not explicitly stated but participants were recruited from "dances geared towards intellectually disabled"	Ethnographic Observations and interviews	Dramaturgical perspective	To identify, describe and understand a new generation's possibilities and hindrances for sexuality and love in view of the changes in society.	7*
Study 7 Bane et al. (2012)	Relationships of people with learning disabilities in Ireland	Ireland	97 men and women	Researchers with intellectual disabilities invited participation	Focus groups. Included people with intellectual disabilities as researchers	Not Stated	To identify what people with learning disabilities in Ireland thought	18

Reference	Title	Country	Sample	Recruitment	Data Collection	Analysis	Aim	CASP Score
				from service organisations and self-advocacy groups			about friendships and relationships	
Study 8 Bernert and Ogletree (2013)	Women with intellectual disabilities talk about their perceptions of sex	USA	14 women	Potential participants were recommended for the study by agency administrators due to their experiences of sexuality	Ethnographic Formal and informal observation and in-depth, semi-structured interviews	Not stated	To explore sexuality in the lives of women with intellectual disability	16
Study 9 Fitzgerald and Withers (2013)	'I don't know what a proper woman means': What women with intellectual disabilities think about sex, sexuality and themselves	UK	10 women	Access to participants was gained through "other professionals" working in the locality	Semi-structured interview	Thematic Analysis	To investigate the sexuality and sexual identity of women with intellectual disabilities.	19
Study 10 Kelly, Crowley, and Hamilton (2009)	Rights, sexuality and relationships in Ireland: 'It'd be nice to be kind of trusted'.	Ireland	15 men and women	Self-elected participation from community service	Focus Group	Thematic Analysis	To understand people with learning disabilities' views, experiences and aspirations of	17

Reference	Title	Country	Sample	Recruitment	Data Collection	Analysis	Aim	CASP Score
							sexuality and examine desired assistance,	
Study 11 Hollomotz (2009)	'May we please have sex tonight?' – People with learning difficulties pursing privacy in residential group settings.	UK	15 men and women	Self-elected participation as self-advocates involved in a service user consultation on the formulation of a local relationship policy	Focus Group	Not stated	To examine privacy and sexual relationships of people with learning disabilities.	7*
Study 12 Lesseliers and Van Hove (2002)	Barriers to the development of intimate relationships and the expression of sexuality among people with developmental disabilities: Their perceptions.	Belgium	34 men and women	Potential participants recruited by residential or day care staff	In-depth, semi-structured interviews	Not stated but described	To understand how people with learning disabilities experience and interpret their environment and feelings in the context of their relational and sexual lives.	18
Study 13 Turner and Crane (2016)	Pleasure is paramount: Adults with	USA	5 men and women	Participants were recruited via	Semi-structured	Thematic Analysis	To examine how adults with learning	19

Reference	Title	Country	Sample	Recruitment	Data Collection	Analysis	Aim	CASP Score
	intellectual disabilities discuss sensuality and intimacy.			agency professionals using a purposeful sampling method	interviews and observations		disabilities describe their experience and expression of romantic, and/or sexual relationships	
Study 14 White and Barnitt (2000)	Empowered or discouraged? A study of people with learning disabilities and their experience of engaging in intimate relationships	UK	8 men and women		Semi-structured interviews	Qualitative methodology emerged from hermeneutic phenomenology	To examine whether people with learning disabilities feel empowered or discouraged when engaging in intimate relationships	16
Study 15 Lafferty, McConkey, and Taggart (2013)	Beyond Friendship: the nature and meaning of close personal relationships as perceived by people with learning disabilities	Ireland	16 heterosexual couples	Recruited through providers including supported living services, a residential service, a daycare centre and an advocacy organisation	Semi-structured interviews	Grounded Theory	To uncover the experiences of couples in a close personal relationship, the nature of these relationships and the meaning they ascribe to them.	17

Reference	Title	Country	Sample	Recruitment	Data Collection	Analysis	Aim	CASP Score
Study 16 Neuman and Reiter (2016)	Couple relationships as perceived by people with intellectual disability – implications for quality of life and self-concept	Israel	20 heterosexual couples	Recruited from services that provided assisted living	Observations and semi-structured interviews	Thematic content analysis	To uncover how intimate relationships are perceived by people with intellectual disability.	14
Study 17 Rojas, Haya, and Lázaro-Visa (2014)	'My great hope in life is to have a house, a family and a daughter': Relationships and sexuality in intellectually disabled people	Spain	16 men and women	Recruited through agencies promoting self-determination and self-advocacy	Semi-Structured interviews and images	Thematic coding process	To answer questions about sexuality in the lives of people with intellectual disability.	15
Study 18 (Rushbrooke, Murray, & Townsend, 2014)	The experiences of intimate relationships by people with intellectual disabilities: A qualitative study		9 men and women	Recruited from adult community learning disability services	Semi-structured interviews	Interpretive Phenomenological Analysis	To contribute and expend the current evidence base for sexuality and intimate relationships for people with learning disabilities to bridge the gap between policy and practice.	19

18 articles were identified as meeting the inclusion criteria by the lead researcher. Of these 18 articles, a random selection of eight were reviewed by an independent researcher. The independent researcher also reviewed a random selection of eight articles which were excluded from the synthesis. When checked against the inclusion criteria, the independent researcher and the lead researcher had 100% agreement of the selected articles to be quality assessed.

Selecting the studies

In order to select the final studies, identified potential studies were read and re-read and examined in terms of quality using the Critical Appraisal Skills Programme qualitative checklist (CASP qualitative checklist) (Critical Appraisal Skills Programme, 2017) to appraise each paper (Table. 3). The CASP qualitative checklist is a specially designed tool to enable researchers to evaluate qualitative research papers. Each paper was scored on a scale of 0-2 depending on the amount of information the paper provided in each category (as described by Duggleby et al. (2010) and Rushbrooke, Murray, and Townsend (2014)). Articles that scored ten or less were excluded from the review. Four papers were randomly selected and scored by an independent researcher. An interrater reliability analysis using the Kappa statistic was performed to determine consistency among raters; Kappa = 0.54 ($p<0.001$) indicating moderate agreement between the two researchers (Landis & Koch, 1977). Two articles were excluded based upon a CASP score of lower than 10.

Analysis and synthesis of the selected studies

The method used to guide the synthesis followed that of meta-ethnography developed by Noblit and Hare (1988) and based on the particular method described by Malpass et al. (2009), for example the themes identified by the paper authors (the second order constructs) become the data rather than the quotes themselves (the first order constructs).

The selected studies were carefully read and re-read in order to identify the main concepts and details were recorded (e.g. setting, participants etc) to provide the context for interpretations made of each study. The next step involved determining how the studies were related to each other. This involved looking across the different papers for common and recurring concepts. In this way, the studies to be synthesised were treated in a similar way to primary data. Next, to translate the second order constructs across the 16 papers, each was entered into a spreadsheet with the corresponding paper number in the final column and a

Table. 3. *Included and excluded (*) articles according to CASP qualitative checklist.*

Study Number	1	2	3	4	5	6*	7	8	9	10	11*	12	13	14	15	16	17	18
1. Clear statement of aims	2	1	2	2	2	1	2	2	2	2	0	2	2	2	2	2	1	2
2. Qualitative methodology appropriate	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
3. Appropriate research design	1	2	2	2	2	0	2	2	2	1	0	2	2	2	2	2	2	2
4. Appropriate recruitment strategy	1	2	2	2	2	0	1	2	2	2	0	2	2	1	2	1	2	2
5. Consideration of data collection	1	2	2	2	2	0	2	2	2	2	1	1	2	2	2	1	2	2
6. Consideration of research relationships	0	1	0	2	1	2	2	0	2	1	0	2	1	0	0	0	0	2
7. Ethical issues considered	0	2	2	2	2	0	2	2	2	2	2	2	2	2	2	2	2	2
8. Rigorous data analysis	1	1	0	2	1	1	1	1	2	1	0	1	2	1	1	1	2	2
9. Findings clearly stated	2	2	2	2	2	1	2	2	2	2	1	2	2	2	2	1	1	2
10. Value of the research	2	1	1	2	1	0	2	1	1	2	1	2	2	2	2	2	1	1
Total Score	**12**	**16**	**15**	**20**	**17**	**7**	**18**	**16**	**19**	**17**	**7**	**18**	**19**	**16**	**17**	**14**	**15**	**19**

summary definition was provided for each one, often using the original terminology provided in the papers where appropriate. We were then able to read and re-read all of the second order summaries in order to determine overlap and write a translation of each second order construct across all 16 papers. The final stage involved synthesising the translations by creating third order constructs that represent the views and interpretations of the synthesis. Synthesising of translations and development of the third order constructs was guided by the CMM framework of layered contexts: episode, identity, relationship and culture. This stage was completed by the research team through discussion and feedback and finally expressed in terms of themes and key concepts (Table. 4).

Synthesis

Four core themes were identified across the studies; 'Sociocultural Norms' within the context of cultural beliefs of PWID, 'Under Others Power' within the context of relationships, 'Sexual Identity' within the context of identify, and 'Sexual Experience' within the context of episode. A number of subthemes were identified and are described within each layer of context.

Cultural Beliefs of PWID: Sociocultural Norms

PWID appeared to ascribe to very traditional sociocultural norms in terms of sexuality and intimate relationships. The majority of papers reported that PWID had a desire to be involved in an intimate relationship. PWID in these studies expressed dissatisfaction with being single and felt they needed to have a partner to be fulfilled. However, some did report that having a relationship was not important for them and tended to reference external, social constructions of relationship difficulties as deterrents: e.g. they would have to buy gifts for their partner and it would be expensive.

Some PWID perceived it was easier for non-disabled people to maintain and establish relationships. Many expressed a desire to have a partner of average intelligence, but all who had partners had partners with an intellectual disability. They believed that perceptions of beauty and stereotypes of intellectual disabilities acted as a barrier to forming relationships with others. PWID reported feeling they were treated unfairly in how decisions about their relationships are made.

Many PWID believed being in a relationship made them happier, more confident and increased their independence. Intimate relationships were seen by PWID as a source of support and important to provide a sense of security, shared mutual connection, reciprocity

Table. 4. *Third order constructs and synthesised translations.*

3rd order constructs	Paraphrasing of second order constructs	Summary definition (translation) of the second order construct	Papers that include the 2nd order construct
Cultural Beliefs of PWLD: Sociocultural Norms	Gender Roles	Gender stereotyped ideas about men and women in relationships according to gender roles expected within social norms.	5, 7, 9
	Traditional views on Marriage	Conventional and stereotyped view that sex only occurs within a monogamous marriage and only for the purpose of procreation.	3, 4, 5, 7, 8, 12, 13, 14, 15, 16, 17, 18
	Desire for relationships	A strong desire to be involved in an intimate relationship.	3, 5, 7, 10, 12, 13, 15, 17, 18
	Positive view of relationships	Being in a relationship associated with feeling happier, more confident and increased independence.	3, 4, 10, 12, 14, 15, 16, 18
	Choosing a partner	Searching for desired characteristics in a partner.	5, 10, 13, 14, 18
	No atypical relationships	No consideration of anything other than a heterosexual identify.	5, 8, 9
	Inequality	Perception that maintaining and establishing relationships is easier for non-disabled people.	3, 9, 10, 17, 18
Relationships: Under Others Power	Prohibition	Agencies prohibited expressions of sexuality ranging from displays of affection to intercourse.	1, 3, 9, 10, 12, 13, 18
	Involuntary Separation	Fear of losing a valued person or relationship due to one person in the relationship being moved to another supported home.	9, 10, 12, 16, 17
	External Power	The external management of relationships by staff and families	3, 4, 5, 9, 10, 12, 14, 16, 17, 18
	Restrictions	Excessive rules and restrictions related to sexual behaviours and relationships.	3, 4, 5, 10, 12, 14, 17, 18
	Adolescent relationships	Language and descriptions akin to adolescent relationships.	4, 5, 7, 9
	Sexual education	Incomplete or inaccurate knowledge of relationships, sex, bodily organs and function.	3, 5, 8, 9, 10, 12, 13, 14, 17
	Acquire knowledge about sex	Knowledge of sex acquired by through random and opportunistic ways.	5, 10, 12, 13, 18

3rd order constructs	Paraphrasing of second order constructs	Summary definition (translation) of the second order construct	Papers that include the 2nd order construct
	Fearful consequences	Only associated sex with sickness, disease and negative consequences.	3, 5, 8, 9, 12, 18
	Support	Desired to be supported to maintain and establish relationships, express sexual needs and manage relationship conflicts.	2, 9, 10, 12, 14, 15, 18
	Isolation and Loneliness	Professionals thought it is adequate to provide activities for PWLD to combat loneliness but failed to facilitate relationships beyond friendship.	13, 15
	Assistance	Lives revolved around reliance on assistance to provide practical support to assist adaptive behaviours.	1, 4, 7, 13, 15, 18
Identity: Sexual Identity	Sexual pride/sexual self-identity	Positive view of sexuality and their erotic potential to be sexual.	8, 12, 13, 18
	Distance self from sexuality	Ambivalence and denial towards own sexuality, anxiously defending against, hiding or suppressing the possibility of sexual relationships.	4, 5, 7, 9, 12, 13, 18
	Adult identity and Autonomy	Identified as being an adult, aware they have rights and believed they should have choices.	1, 2, 3, 15
	Internal conflict	Internal battle between the sexual norms prescribed to PWLD by the external world and their own internal sexual feelings and desires.	2, 4, 9, 13
	Rejection of Disability-Identity	Did not identity as having a learning disability and identified themselves as 'normal'.	1, 5, 9
Episode: Sexual Experience	Sexuality of middle field	Kissing, cuddling, hugging, hand holding etc. but not sexual intercourse.	4, 12, 13, 16, 18
	Communication	Communication with partner increased respect of boundaries.	12, 13
	Masturbation	Some did not know what masturbation was but others saw it as the only outlet to fulfil their sexual desires.	3, 5, 12, 13
	No pleasure	Rare or no pleasure language used by PWLD.	4, 8, 9, 12
	Negative Sexual Experiences	Some PWLD had past experiences of sexual abuse and exploitation which influenced views and engagement in intimate relationships.	5, 8, 12, 14, 15, 16, 18
	Protective Sexual Strategies	Engaged in self-imposed abstinence, avoidance or secret sexual behaviours to avoid perceived negative consequences and reactions by others.	1, 3, 5, 8, 10, 12, 18

and companionship. PWID in these studies described being committed and devoted to their relationship and enjoyed talking to each other, spending time together, taking care of each other and buying each other gifts.

However, PWID gave no consideration of anything other than a heterosexual relationship within the studies. Many could not identify or name different sexual orientations and for the majority of those that could, they described these as ‘wrong’ and ‘horrible’. Additionally, three quarters of the studies reported on PWID’s traditional views about marriage. PWID in these studies held a conventional and stereotyped view that sex only occurs within a monogamous marriage and only for the purpose of procreation. This message appeared to be passed down through the views of professional staff and families. If unmarried, PWID believed that as a very minimum sex should be with someone you really love, rising to feelings of shame at engaging in pre-marital sex.

Most PWID in these studies expressed a strong desire for future commitment, marriage and the possibility of having children. For many, marriage signified freedom, independence, happiness and a better future. For some, they had no desire to marry because of the belief it would be too difficult: paperwork associated with marriage, helping children with homework, too expensive and might end in quarrels and fights.

Three studies highlighted the gender stereotypical ideas PWID hold about men and women in relationships, according to gender roles expected within social norms. These beliefs seem to be reinforced by the environments that PWID often found themselves in, for example day centres, whereby women took part in activities such as knitting and sewing and men engaged in activities such as woodwork. Additionally, support staff were usually women and managers or positions of power were usually occupied by men.

Relationships: Under Others Power

PWID experienced excessive rules and restrictions imposed by support staff and caregivers in relation to sexual behaviours and intimate relationships. In some cases, PWID experienced being chastised by staff for engaging in ‘restricted’ behaviours. PWID felt as though agencies prohibited expressions of sexuality ranging from displays of affection to sexual intercourse.

Some PWID reported experiencing pressure to end relationships and feared the consequences of engaging in ‘prohibited’ behaviours. Fear of losing a valued person or relationship due to one person being moved to another supported home was identified in five studies. Established relationships did not appear to be considered when organising social housing and many felt forced to end relationships due to moving. Sometimes this move was experienced by PWID as a punishment for engaging in ‘prohibited’ behaviours

and the fear of involuntary separation was reported as influencing decisions to commit to future relationships.

Feelings of being monitored and not trusted were reported by PWID who often felt as though they were not offered appropriate levels of privacy. Despite wishing to engage in intimate or sexual relationships, they felt they were never provided with the opportunity to be alone with their partner.

Language and descriptions reported in the research were akin to adolescent relationships. PWID reported being perceived by others as 'grown up children' and treated in the same manner; caregiver impulses to keep them safe denied them the rights to experience full life and learn from their mistakes.

A number of studies reported on the external management of PWID's sexuality and relationships. In these studies, PWID viewed caregivers as the greatest support or barrier to their sexuality. Some felt they could discuss relationships with their family members but others felt as though family and staff held the power to provide or withhold sexual information, living arrangements etc and these decisions were sometimes made against their will. Most experienced constant warnings and restrictions by family and staff to abstain and protect themselves and others from their sexuality. Depending on the nature of the external power, PWID reported expressing powerless positions whereby they felt unable to assert their sexuality and felt forced to follow the dominant opinions of others.

Over half of the studies reported that PWID held incomplete or inaccurate knowledge of relationships, sex, bodily organs and function. Information provided by staff or families tended to focus on protective measures, basic function and negative consequences. Some PWID described their lack of knowledge as a barrier to engaging in sexual behaviours. Perhaps due to a lack of information, many PWID described acquiring their knowledge of sex and sexual behaviours through random and opportunistic ways: for example, watching others on television, reading about it in magazines or by watching pornography. This appeared to lead to partial, inconsistent and skewed views of sex and relationships. For some, this skewed view of sex left them believing sex would be too aggressive and therefore anxiously avoided it. PWID received numerous messages of sex as 'dangerous' and some were solely communicated the negative consequences of sex. Within the studies, many PWID described sex as 'dirty' and 'disgusting' and were afraid of consequences such as pregnancy and STDS. Some could only associate sex with sickness and disease.

PWID desired to be supported to maintain and establish relationships, express their sexual needs and help manage and resolve relationship conflicts. PWID valued talking to someone about their relationships (e.g. care staff, parent, friend). However, they also

reported very different experiences in actually receiving this support, ranging from caregivers outright refusing to provide this support, leaving PWID with no opportunity to talk about their relational and sexual feelings, to feeling well supported in their relationships.

PWID lives appeared to revolve around reliance on assistance to provide practical support to assist adaptive behaviours, for example they needed transportation to maintain and facilitate personal relationships. In these cases, caregivers acted as gatekeepers to socialisation and PWID felt they had infrequent opportunities to meet with others and felt unable to socialise outside of their pre-arranged social groups. Due to this, PWID could experience loneliness and a lack of intimacy in their lives. They reported that professionals could think it adequate to provide activities for PWID to combat loneliness but this failed to fulfil their need for intimacy.

Identity: Sexual Identity

Some PWID did not identify as having an intellectual disability, but understood this was a label given to them by others. Instead, they identified themselves as being as 'normal' as everyone else and strived to live their life this way. Those who did accept the intellectual disability label struggled to understand and talk about what it meant.

Four studies described how PWID were able to hold a positive sexual identity and were aware of their erotic potential to be sexual. They noticed themselves as sexually desirable to others and had a desire to engage in sexual activities with a partner or future partner. One study reported that most of the participants had engaged in sexual intercourse during their lives, but actual experiences of engaging in sexual intercourse and sexual behaviours were largely missing from the research. An erotic self-identity was also present in more subtle contexts such as having hope for the future, holding a desire to be seen by others as adults with rights, choices and aspirations to be accepted as sexual beings. Whereas more overt expressions were much more rarely described in the studies.

A more persistent theme described by seven studies identified PWID's tendency to distance themselves from their sexuality. PWID in these studies portrayed ambivalence and denial towards their own sexuality. The studies described how PWID anxiously defended against their sexuality by hiding or suppressing the possibility of any form of sexual relationship, as though they did not in fact identify as sexual beings. The studies described how many PWID find discussing sexuality embarrassing and try to distance themselves from talking about sex, making indirect references to physical relationships.

A number of studies referred to the internal battle PWID experienced when considering or expressing their sexuality. This conflict arose between the sexual norms

prescribed to PWID by the external world (e.g. staff, families and society) that they should not act on their individual needs and desires and their internal sexual feelings and desires. PWID felt as though their own wishes could be engulfed by opposing influences and this often led to feelings of shame.

Episode: Sexual Experience

Many PWID expressed their sexuality through intimate behaviours such as kissing, cuddling, hugging and hand holding but did not engage in more explicitly sexual behaviours including sexual intercourse. It seemed as though many participants did not want more from their relationships than these behaviours. These behaviours were also felt by participants to be important in order to build a relationship and indicated emotional closeness, intimacy and enjoyment within a relationship.

Two studies that reported on PWID's experience of sexual behaviours identified communication between partners as key. PWID felt that talking about their sex life created a basis whereby they could carefully explore and respect each other's boundaries. The women in the studies wanted to be treated gently and tenderly in personal interactions and the men also described wanting a peaceful approach. Being open with communication allowed the men to be tolerant and accepting of the women who did not want to engage in intercourse. The experience of being patient and gentle before and during intimate experiences, seemed to allow partners to be more open to new experiences.

Mixed views were presented on engaging in masturbation. Some studies described participants as not knowing what masturbation was or what it involved whereas others described participants as actively engaging in masturbation, describing it as an important aspect of their lives as the only outlet to fulfil their sexual desires and release tension. However, it was far more common for studies to talk about negative sexual experiences rather than positive, with seven studies detailing negative experiences of sexual contact. Within these studies, some PWID had past experiences of sexual abuse and exploitation. These experiences seemed to strongly influence their negative views of intimate relationships and their decisions on how they engaged in future relationships or not, as the case may be. Not being able to talk to others (e.g. support staff) about how they were feeling or their experiences, made PWID more vulnerable to abuse.

Four of the studies reported that language used by PWID to describe sex rarely contained words that described pleasure. Although the studies reported that both genders faced similar experiences, in terms of gender differences, women in these studies were more likely to recount unsatisfying or abusive sexual experiences and rarely appeared to experience sexual desire. Many women in these studies appeared to consent to passive

pleasure-less sexual acts in the belief it was their role as a woman rather than for their sexual pleasure. If pleasure was described, this was usually an extension of the overall mutuality of the relationship and whilst both men and women could find sexual relationships satisfying these relationships were not stimulating; very few could describe an orgasm.

PWID appeared to engage in several protective sexual strategies to avoid either unwanted sexual consequences or reactions from others. For some, they engaged in self-imposed abstinence to protect against negative consequences such as AIDS, pregnancy and negative reactions from staff and families. For some PWID who had experienced abuse, they reported avoiding all 'risky' situations to protect themselves against the occurrence of potential future abuse. Additionally, in response to restrictive and prohibitive climates and to prevent upset and negative reactions from others, some PWID felt they could only assert their independence by resorting to secrecy to satisfy their sexual needs and engage in intimate activities by opportunistic and surreptitious means.

Discussion

This meta-ethnographic synthesis brings together the voices of PWIDs and provides the literature with a view of the complexity of the issues involved in the topic of PWID's sexuality.

Using a CMM framework (Figure. 1), we have identified how PWID's sexuality exists within the contexts of the cultural beliefs of caregivers (as described in the existing literature: hypersexual, asexual and rights-based), cultural beliefs of PWID (sociocultural norms), relationships (under others power), identity (sexual identity), and episode (sexual experience). By adapting the CMM hierarchical model to account for the three cultural

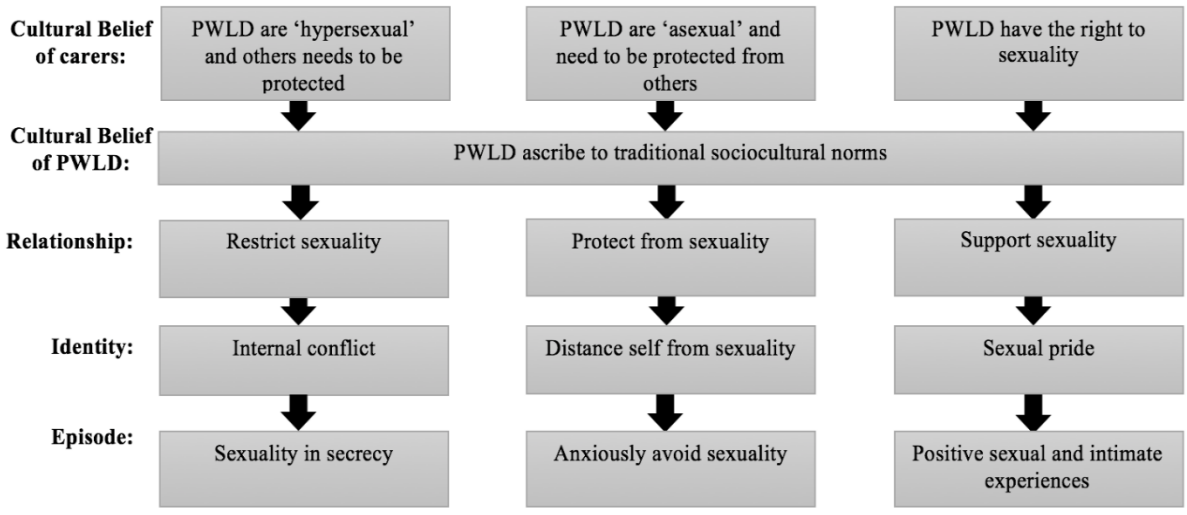

Figure 1. PWID sexuality within the CMM hierarchical model

beliefs held by others, we are able to notice repetitive patterns between PWID and their caregivers, professionals and families that inhibit or facilitate PWID's right to sexuality. It appears as though caregivers can be working within all three contexts at one time, and can move between contexts at different times. What appears to be most significant is how these contextual forces influence the communication acts in the subsequent contexts and this process will be described and discussed.

Moving through the model, we can see how PWID ascribe to very traditional sociocultural norms in terms of sexuality. They hold traditional views on gender roles and marriage and associate happiness with aspiring to be in a traditionally defined heterosexual relationship. These cultural beliefs seem to exist based on information provided to them by their external environment (e.g. caregivers, professionals, families, the media etc). If the cultural message is that PWID are 'hypersexual' and others should be protected from their sexuality, then even if PWID desire to express their sexuality in line with traditional sociocultural norms, the relationship context between the PWID and caregivers will be more influenced by the higher level of culture. Resulting in caregivers 'restricting' PWID from expressing their sexuality rather than focusing on the individual's needs and desires. This seems to co-construct a meaning of internal conflict at the identity level as PWID report feeling desire but also feeling it is not acceptable within the wider context. In the context of the episode, this then means PWID act to communicate their sexuality by expressing it in secrecy, thus putting themselves at risk and at a greater vulnerability to negative sexual and intimate encounters.

If the cultural message is that PWID are 'asexual' and need to be protected from their own sexuality, then again their desire to express their sexuality will not have the strongest contextual force. The relationship level will be more influenced by the higher cultural context so that caregivers act to protect PWID by not exposing them to their potential sexuality. These contexts co-construct a meaning of distancing the self from sexuality in PWID as they describe sexuality as something 'funny' or 'embarrassing' or unfortunately but more commonly, 'dangerous' or 'disgusting'. Within the context of episode, PWID then communicate their sexuality by trying to protect themselves from it: they act to anxiously avoid sexual or intimate encounters or practice abstinence. This pattern of communication also appears to leave PWID at risk and vulnerable to negative sexual and intimate encounters.

If the cultural message is that PWID have the right to express their sexuality and the PWID's culture is that they wish to purse their sexuality within their cultural norms, then the relationship of the caregivers to the PWID communicates emotionally and practically supportive acts. These contexts filter down to construct a meaning of 'sexual

pride' for PWID as they endorse their sexuality and become more aware of their sexual potential. In the context of the episode, PWID can communicate their sexuality by exploring and engaging in positive, pleasurable sexual experiences and intimate relationships characterised by open and respectful communication between partners.

By examining the model we can see that the only opportunity that leads to positive outcomes for the sexuality of PWID are when right-based cultural messages produce a dominant cultural force that influences the other layers of context to support sexuality, encourage and foster sexual pride and embolden PWID to positively explore their sexuality. However, this meta-ethnographic review has shown that out of the three hierarchies, evidence for the rights-based model is least reflected in the data. PWID described their caregivers as the biggest support or barrier to expressing their sexuality and the studies reported far more instances of barriers to sexuality than support. Sexual pride was only reported by four papers, and only one of these did not consider this an exception to the majority of negative sexual identity stories. However, it is important to note that more positive views of sexuality are reflected in more modern papers that may reflect a contemporary shift in the cultural attitudes of caregivers.

Perhaps most striking is the distinct lack of studies that report on positive sexual experiences and intimate relationships in the lives of PWID. This may be a methodological issue; perhaps contextual forces have been so strong that research has commonly focused on the negatives rather than the positives. However, due to the number and breadth of studies that have now been conducted in this area and have been reviewed by this synthesis, it now seems more likely that the 'hypersexual' and 'asexual' contextual forces are influencing the layers of context in such a way so that the majority of PWID are unable to have positive sexual and intimate experiences within the episode context.

A meta-synthesis examining caregiver's attitudes towards PWID's sexuality highlighted many caregivers held cultural beliefs within a right-based context, and although caregivers experienced hypersexual and asexual cultures in the research, the authors describe these themes as present but not pervasive (Rushbrooke et al., 2014). Despite this, the current meta-ethnographic synthesis examining PWID's views and experiences has found a real lack of evidence documenting the rights-based context of supporting PWID to explore their sexuality. It appears as though there are distinct differences between the stories told by caregivers and stories lived: although the majority of caregivers may hold rights-based cultural beliefs about PWID's sexuality, these beliefs may not hold the greatest contextual force when hypersexual and asexual contexts are present and may not translate into positive communicative acts that respond to the individual need and desire of PWID. As Rushbrooke et al. (2014) describe, caregivers of

PWIDs can feel like they must play the role of 'protector and risk manager' and perhaps this references a higher contextual force that may be beyond the scope of this study: the political and legal framework that influences the culture of caregivers. This highlights the need for caregivers to feel more confident using the legal framework to make decisions based on their rights-based cultural beliefs that will increase autonomy and independence in PWID when exploring their sexuality.

The studies included in this meta-ethnographic synthesis were conducted in a range of different countries each with their own unique culture. For example Yau, Ng, Lau, Chan, and Chan (2009) explored how PWID experienced their sexuality within the culture of Hong Kong, where the neo-Confucian Chinese concept of denouncing sexual intimacy intersects with western values of pleasure. However, despite the differences in culture, there did not appear to be significant differences in themes across the studies as Table. 4 displays. The predominant cultural beliefs of viewing PWID as 'hypersexual' or 'asexual' appeared to be present in all cultures, perhaps indicating the power of this contextual force.

While this meta-ethnographic synthesis has used a CMM framework to focus specifically on sexuality within the lives of PWID, this framework could be used to examine the cultural impacts of multiple forms of sexuality. For example, the experience of other minority groups, such as people with physical disabilities, are often influenced by cultural beliefs of 'asexuality' which influence their encounters with professionals to limit the exploration of sexual pleasure (Tepper, 2000). In fact, when examining the wider sexuality literature, it becomes clear that cultural beliefs not only influence the sexual experience of PWID, but other minority groups and their positive and negative impact needs to be explored further. However, despite similarities with other groups, there appears to be an important and significant difference when examining the sexuality of PWID with regards to the number of contrasting cultural beliefs that can leads to significantly different expressions of sexuality.

Limitations

This meta-ethnographic synthesis utilised the CASP in order to only include research of a medium to high quality. However, there is a potential risk with this approach that valuable insights into the topic may be excluded from synthesis. Research rated as 'low quality', for example due to methodological flaws, may nonetheless generate new insights and rich data, whereas methodologically sound research might lack richness and lead to poor insight into the phenomenon (Dixon-Woods et al., 2007). However, the studies excluded from this research did not appear to offer additional insights not already

captured by other studies included in this review. Additionally, findings did not appear to vary according to the quality of the studies and therefore richness of the data was determined not to have been lost due to the use of CASP.

No date range was included in the initial search in order to maximise search results. However, the included search terms may not have fully reflected the historical perspectives of intellectual disabilities. For example, it may have been beneficial to include search terms such as 'mental retardation' during the initial search.

Implications for practice

This meta-ethnographic synthesis, in combination with other research (e.g. Rushbrook et al., 2014) has highlighted the default position of caregivers can be to protect and restrict, rather than support the sexuality of PWID to develop in a positive and affirming way. These messages are then taken up by PWID, resulting in their sexuality being avoided or conducted in secret, potentially exposing themselves to risk and lack of support. We could hypothesize many reasons why this might be the case, for example, that there may be a history of unwanted sexual contact of abuse, problems with consent, communication or understanding of sex. In a busy residential home a policy of no sexual relationship might make thinks clearer and easier to maintain boundaries and the potential for legal action may make caregivers overly cautious 'just in case'. However, these contexts offer no room for PWID to engage in positive sexual experiences and develop affirming and intimate relationships. Positive intimate relationships are often not seen as options by caregivers or PWID, when they could be with appropriate support for both PWID and their caregivers.

PWID will often have received some level of sex education, and information about privacy, appropriate touching and keeping safe. This study suggests that this could be further extended into a rights-based discourse and include information about sexual pleasure, sex as acceptable and what different people might like (e.g. that you do not have to be married to have sex, same-sex sexuality, different sexual acts that give pleasure like oral sex, etc.).

Facilitated group supervision for caregivers can help unpack some of the discourses of sex being discouraged or viewed as unsafe. The group could explore what barriers they face in adopting a rights-based approach to the sexuality of those in their care, and how some of these might be overcome. It might be useful for caregivers to reflection on what difference to understanding situations previously seen as 'challenging behaviour' a rights-based discourse might offer, and what alternative actions might lead from this. Institutional policies around sexuality could be revisited to consider what might

be permissible in what circumstances. Transparent discussions need to happen with family and professional staff so that the same approach is offered in different settings so as to minimise confused messages for PWID and prevent conflict with and between those around them. There may be caregivers' groups that could offer support. Rather than this meta-ethnographic synthesis offering a prescriptive way on how to adapt a rights-based approach to sexuality, we hope that it can be used as a tool to open up discussions about this possibility and revisit current practice and policies.

This meta-ethnographic synthesis also highlights a need for future research to focus on PWID who experience their sexuality within a rights-based context: how does this influence their relationships with caregivers? Their identity? Episodes of sexuality expression? And what can we learn from these contexts that will improve the lives of PWID? Understanding these questions might also add understanding to why a rights-based approach is not currently taken up by caregivers, despite their knowledge of it.

Conclusion

PWID have the right to express and explore their sexuality. However, this meta-ethnographic synthesis that explored PWID's views in regards to their sexuality has highlighted overwhelmingly negative experiences and perceptions. As existing literature describes, caregivers of PWID can draw upon 'hypersexual', 'asexual' and 'rights-based' contexts. This meta-ethnographic synthesis has found evidence for the application of the hierarchical CMM model that appears to suggest caregivers overarching contextual beliefs about PWID's sexuality influences subsequent layers of context that act to either inhibit or facilitate positive expressions of sexuality. It appears rights-based cultural messages provide the only context that leads to positive outcomes for the sexuality of PWID. By influencing subsequent layers of context to support sexuality, rights-based cultural messages encourage and foster sexual pride and embolden PWID to positively explore their sexuality. However, qualitative research that explores PWID's sexuality within a rights-based context is significantly lacking and is a much needed area for future research. We hope that services will use the CMM model identified by this research as a framework to support the reflective-practice of caregivers in the future. Caregivers should also be supported to work within a rights-based context that allows them to feel more confident applying the legal framework to respond to individual needs and desires and therefore improve the social worlds of PWID.

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Amendment Number	Comment	Page and Comment
1	A better set up of the study rationale is needed in the Introduction. The purpose of the study seems to just be tagged on to the end of the "Coordinated Management of Meaning" section, but I would recommend it have its own heading as "Study Purpose" to ensure a better transition from the CMM to the study purpose and provide succinct argument for why this study is needed—i.e., why is applying CMM and using an ethnographic qualitative review needed to address the current gaps in the literature?	A paragraph explaining the study purpose has been added before the method section.
2	It appears authors revised the title to reflect ID rather than LD in the manuscript, but this change is not reflected in the title that appears in the system generated title.	Revised
3	Was there a specific date range for the articles? Somewhere in the inclusion criteria section of the Methods it should be clearly stated what the date range was. This is important because if they went back many years, the search term "mental retardation" should have probably been included as well. This may be a limitation that needs to be stated.	In Table 1: search terms, the search criteria states that "all dates" were searched. I have included this comment in the limitations section: "No date range was included in the initial search in order to maximise search results. However, the included search terms may not have fully reflected the historical perspectives of intellectual disabilities. For example, it may have been beneficial to include search terms such as 'mental retardation' during the initial search."
4	The quality of the writing needs to be enhanced. There are a number of grammatically incorrect or run-on sentences throughout, which distract from the flow of the paper. I also recommend paragraphs include at least 3 sentences.	**Throughout:** Term Carers changed to caregivers Changes to the writing style and grammar have been made throughout the document so that it reads better.

	I've provided some examples below of sentences that need to be revised, but there are a number of others and this paper would benefit from a thorough edit prior to publication. Is "Carers" the appropriate term? I typically see the term "caregivers" in the literature.	